

February 21, 2007

Connecticut Legislators:

Thank you very much for letting me speak here today. My name is Danny Lemos and in Jan of 2005 I was diagnosed with an aggressive form of Non Hodgkin's Lymphoma. I had just turned 38 years old. The diagnosis was devastating. I was so young and have no history of cancer on either side of my family. And at the time we had two small babies at home and my wife was pregnant with our third.

The Doctors told me that is was a curable form of cancer if I can find could a bone marrow match. My Doctors wanted to me to under go a bone marrow transplant asap but no one in my family was a match. I found out that a person has only a 30 % chance to find a suitable match from a family member. The other 70 % are on their own and hope to get lucky to find a possible donor in one of the marrow registries. The Doctors searched the National Marrow Donor Program registry but there were no matches.

I'll admit before I got cancer I did not know much about bone marrow transplants or the National Marrow Donor Program. I just figured you need a bone marrow transplant and you get one. I was very surprised how few people are registered to be potential donors in this country and how little was being dome to change it. I was in for a sobering awaking. After being treated at Dana Farber with CHOP Chemo for 6 months I went into a short remission. About 6 months later I relapsed. That news was even more devastating than the original diagnosis. The Doctors said there was still a chance for a cure but no match could be found. They would have to do a transplant on me using my own bone marrow. In most forms of cancer the Dr's would rather use some one else's bone marrow stem cells because is has a much higher cure rate. But using my own cells was our only option and that would buy me some time (about a year or so). I did my transplant at Yale using my own stem cells last April. My Doctors suggested when I get out that I get my friends and family together and work with the NMDP to do Bone Marrow Drives to try to find me match. We had our first drive in June 2006 and have had many since then. I was absolutely shocked to find out that the cost getting the perspective donors tested was not covered by insurance. So we had to pay for each donor to be tested ourselves. I could not put a price on my life so we moved a head. Between stem cell drives and other

hospital bills. We have depleted what little money we had in our children's college fund and our savings. Even though the cost to test each person is only around \$60.00 most people can not afford to pay for this test themselves. It is hard enough to get people to come to these drives without charging them the cost of the test as well. And in many cases the best candidates to be bone marrow donors are often the ones that can least afford to pay for their testing. We knew if we had asked people to pay for their testing many of them would just not have come out. It was only when I was put in touch with the RI Blood Center that the cost of having donors tested in RI were covered by their own insurance policies. We have done several with the RI Blood Center and have several more planned in RI and Mass. I would like to start doing bone marrow drives in CT as soon as possible. But we just do not have the money to fund these drives ourselves.

A good example of how few stem cell drives are done in Connecticut.

The NMDP only does one stem cell drive per year at Yale Hospital. I asked the Dr's at Yale why they only do one drive per year and they said money. The NMDP can not afford to do more. They said they need to be doing one per month but they do not have the money. I agreed. But I still could not believe that Yale only does one per year. I said to myself this was Yale Medical Center something has to change. I just shook my head and went home in disbelief. Getting cancer is devastating enough without the fact that you may lose your home, your business and possibly leave your family penniless trying to find a bone marrow match. The insurance companies pay millions for people like me to be treated and have our lives extended and we are great full. But I think they would save a lot of money to help me and many others get cured so we can get on with rebuilding our lives and rebuild what cancer has taken away from us. Think of how many lives would be saved just in the state of Connecticut.

So I ask you to please pass this legislation in support of requiring Connecticut health insurers to cover the cost of these tests. Thank you very much for your time.

Sincerely, Daniel Lemos

Fairfield, CT.